

Speaking to Patients About Diabetes Risk: Is Terminology Important?

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It is estimated that 79 million people in the United States (35% of adults ≥ 20 years of age and 50% of adults ≥ 65 years of age) have mild degrees of hyperglycemia and are thereby at risk for developing type 2 diabetes.¹ Scientific jargon such as “impaired glucose tolerance” (IGT), “impaired fasting glucose” (IFG), and “elevated A1C” may be too technical or cumbersome to use with most patients. Accordingly, preferred terminologies such as “prediabetes” and “at high risk for diabetes” have entered the clinical lexicon and are felt to be simple enough to be understood by the average patient and also sufficiently motivating to encourage lifestyle change to prevent further deterioration to type 2 diabetes.

However, there is debate in the literature regarding which term is most suitable to describe this stage in the development of diabetes. In 2009, the International Expert Committee criticized the term “prediabetes” because it suggests unequivocal progression to diabetes—not an inevitable occurrence²—and advocated for use of the “high risk” terminology instead. The American Diabetes Association, however, has continued to use “prediabetes,” considering it an appropriate description of this at-risk category.³ Other groups, including the World Health Organization and the International Diabetes Federation, have been using different terms for increased diabetes risk, such as “intermediate hyperglycemia,” as well as the more

technical IGT and IFG.^{4,5} However, those descriptors are not routinely used by practitioners in the United States. The American Association of Clinical Endocrinologists preferred “prediabetes” in its 2011 guidelines.⁶

Prediabetes is usually an asymptomatic state. However, it has been associated with certain morbidities, including early stages of neuropathy and macrovascular disease.⁷ For health care providers (HCPs), recognition of this stage is essential because it provides opportunities for patient education about the importance of initiating evidence-based interventions to reduce the risk of diabetes and, potentially, decrease the risk of complications.⁷ Prediabetes, if not treated, indicates an early 5–10% risk per year of progression to diabetes;⁸ the risk may approach up to 50% in 5 years.⁹

Lifestyle interventions and certain pharmacological agents have been shown to delay or prevent the development of diabetes in individuals with prediabetes.^{10–12} Regular aerobic exercise and diet modification leading to weight loss resulted in a 58% reduction in the incidence of diabetes, whereas treatment with metformin was associated with a 31% reduction over a 3-year period.¹⁰ The effects of lifestyle change appear to be sustained for up to a decade,¹³ and both lifestyle and metformin have been demonstrated to be cost-effective.^{14,15}

Unfortunately, data from the 2005–2006 National Health and

Nutrition Examination Survey revealed that < 10% of patients with prediabetes documented by laboratory testing self-reported that they were aware of their condition.¹⁶ Furthermore, the survey also revealed that only one-third of these patients received a recommendation from their HCP regarding lifestyle interventions within the year preceding the survey.¹⁶ Clearly, we need to develop better strategies for communicating diabetes risks to our patients to empower them to enact lifestyle measures to improve their health. The purpose of this preliminary study is to assess which of the two currently used terms for diabetes risk (“prediabetes” vs. “at high risk for diabetes”) has a more profound impact on patients’ insight into the risk factor and on their subsequent willingness and enthusiasm to adopt required lifestyle modifications. Knowledge about patients’ understanding of diabetes terminology may assist practitioners in communicating more effectively with patients.

Methods

During a 5-month period in 2012, we invited 188 patients to complete a survey about diabetes risk terminology in a primary care clinic at a community teaching hospital. Patients aged 30–70 years were approached regarding study participation on arrival to the clinic for their appointment. Patients were asked if they had ever been diagnosed with diabetes, and, if not, they

were offered the opportunity to complete the survey. We did not target any particular groups of patients, such as the obese or those who had risk factors for diabetes. Spanish-speaking patients were given the option to complete the survey in Spanish.

The survey included questions about other major diabetes risk factors, such as family history of diabetes and history of gestational diabetes. We calculated patients' BMI based on their self-reported weight and height. We also asked whether patients believed that they were at risk for diabetes (Table 1).

For both terms ("prediabetes" and "at high risk for diabetes"), we

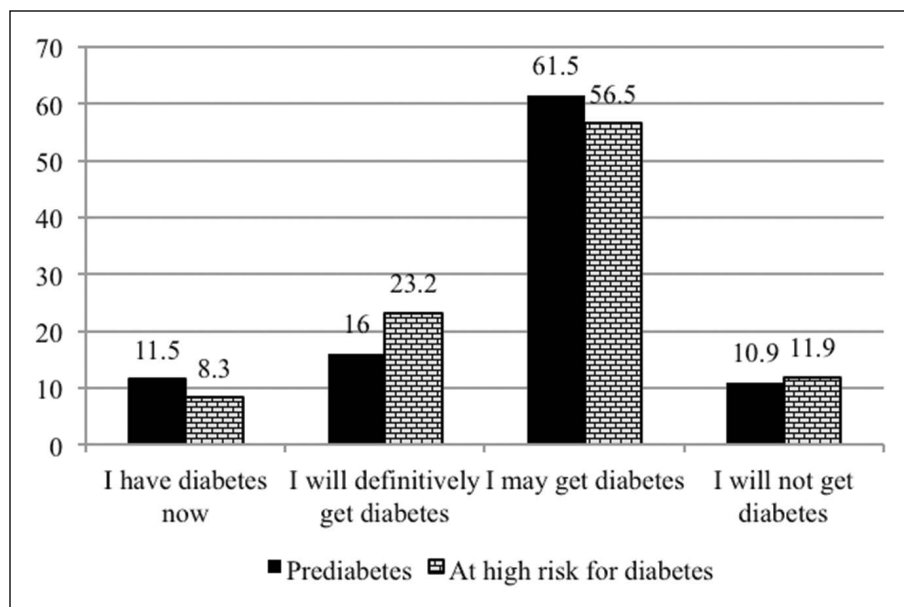


Figure 1. Comparison of patients' understanding of diabetes terminology. Patients had a similar understanding of both of the terms "prediabetes" and "at high risk for diabetes" ($P = 0.50$).

Table 1. Demographics and Risk Factors

| Demographics and Risk Factors | All Subjects (n = 188) |
|--|------------------------|
| Age (years) | 48.4 ± 10.2 |
| Height (m) | 1.65 ± 0.12 |
| Weight (kg) | 84.9 ± 24.3 |
| BMI (kg/m ²) | 30.4 ± 8.7 |
| Sex (n [%]) | |
| Female | 110 (58.5) |
| Male | 78 (41.5) |
| Race (n [%]) | |
| White | 45 (23.9) |
| Black | 71 (37.8) |
| Hispanic | 52 (27.7) |
| Asian | 4 (2.1) |
| Native American | 4 (2.1) |
| Other | 2 (1.1) |
| Unknown | 10 (5.3) |
| Education (n [%]) | |
| < High school diploma | 32 (18.2) |
| High school diploma | 72 (40.9) |
| College | 72 (40.9) |
| Survey taken in Spanish (n [%]) | 27 (14.4) |
| <i>Values for age, height, weight, and BMI are given as mean ± SD.</i> | |

developed questions about patients' understanding and also the importance of such a designation for them personally. We asked patients to imagine a hypothetical situation in which a physician tells them they have "prediabetes" or that they are "at high risk for diabetes." Patients used a Likert scale to score their responses. Patients could also indicate that they did not understand the meaning of these terms. Finally, we asked about patients' willingness to implement lifestyle modifications, such as following a healthy diet, weight loss, and exercise, if they were told that they had either of these states. Patients used a Likert scale in response to these questions.

To determine whether individuals responded differently when told they had prediabetes versus when told they were at high risk for diabetes, a series of McNemar change tests and binomial tests were conducted. We performed Fisher's exact tests to assess patients' understanding and the personal impact of the terminology used. It should be noted

that, because of violation of small expected values by cells, all initial 4 × 4 crosstabs were collapsed into 2 × 2 crosstabs.

To minimize bias, we split the surveys into two groups. One group had the cluster of questions about the term "prediabetes" on the first page, followed by questions about the term "at high risk for diabetes" on the second page. The second group of surveys had the opposite set up, with questions about the term "at high risk for diabetes" on the first page followed by questions about "prediabetes" on the second. The surveys were distributed randomly to equalize the number of patients receiving each sequence. We conducted a series of Fisher's exact tests to determine whether there was an order effect influencing patients' understanding, personal impact, and motivation to adopt lifestyle changes depending on the sequence of questions they received (again using 2 × 2 crosstabs as described above). We considered $P < 0.05$ to designate statistical significance.

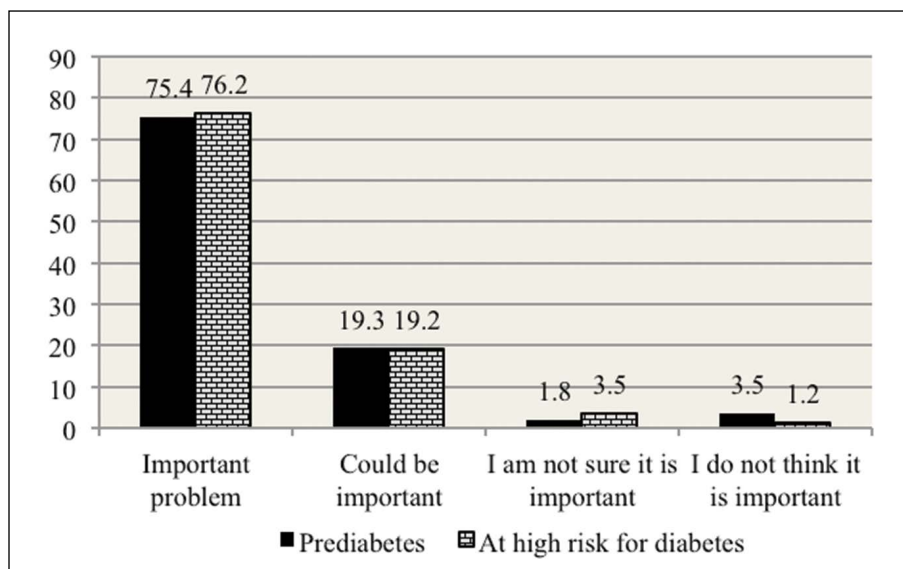


Figure 2. Comparison of personal impact of diabetes terminology. There was no significant difference in personal impact of the terms “prediabetes” and “at high risk for diabetes” ($P = 0.73$).

Results

The majority of patients understood each of these terms similarly as meaning that they may develop diabetes in the future (“prediabetes” 77.5%, “at high risk for diabetes” 79.7%, $P = 0.50$) (Figure 1). There were no significant differences in patients’ understanding or the personal impact of “prediabetes” and “at high risk for diabetes” terms (McNemar test $P = 0.50$, binomial test $P = 0.73$, respectively). The personal impact of both terms also appeared to be nearly identical, with 94.7% of respondents believing that “prediabetes” and 95.4% stating that “at high risk for diabetes” would be an important problem for them ($P = 0.73$) (Figure 2).

No significant differences in responses concerning anticipated lifestyle modifications, such as diet, weight loss, or exercise, were observed between queries concerning these terminologies.

Subjects responded with similarly high motivation for adopting lifestyle modifications, such as diet (97.1 vs. 96.7%, respectively, $P = 1.00$), weight loss (89.8 vs. 92.2%, $P = 0.58$), and exercise (96.4 vs. 95.9%,

$P = 1.00$). Figure 3 summarizes these comparisons.

Patients were more inclined to answer that they “may get diabetes” or “will not get diabetes” when asked first about the meaning of either “prediabetes” or “at high risk for diabetes” compared to the following set of questions about the meaning of “at high risk for diabetes” and “prediabetes” ($P = 0.003$ and $P < 0.001$, respectively). No further order effects were observed for the remaining questions regarding importance and lifestyle changes.

Discussion

From this preliminary study, we conclude that both terms (“prediabetes” and “at high risk for diabetes”) can be used by practitioners to effectively explain the risk of developing diabetes to their patients because they are perceived similarly. Patients had analogous understanding and reported similar personal impact of these terms, as well as apparent equivalent motivation to adopt lifestyle modifications.

This is the first study, to our knowledge, to assess patients’

understanding and perception of common medical terminology used to describe diabetes risk. Awareness about patients’ comprehension of the language that clinicians use when discussing diabetes prevention is essential for effective communication and may also affect an individual’s motivation for lifestyle change. Using different terminology for the same risk factor may conceivably lead to variable perception of its severity and, consequently, affect patients’ inclination to follow prevention recommendations. Most practitioners have limited training and knowledge regarding the perception of different medical terms by patients and, moreover, how said terminology might affect patients and influence their behaviors. Clearly, patient perception of the terminology used when referring to health concepts may be considered to represent a key initial step toward patient-centered care and shared decision-making. In the case of diabetes, patients’ education and engagement will enhance their ability to play an active role in developing individualized treatment goals and strategies¹⁷ and may also improve clinical outcomes.¹⁸

“Pre-disease” stages have been proposed for various clinical entities, including not only diabetes, but also hypertension, cancer, and chronic kidney disease.^{19–21} These terms have emerged mainly to improve understanding of disease evolution on the part of clinicians and researchers. However, it is not known how they might influence patients’ perceptions of risk or their motivation to prevent the fulminant manifestation of the corresponding disease state, whether by adaptation of lifestyle or pursuit of further testing. For example, there has been a debate in the literature regarding the suitability of the term “prehypertension.”^{22,23} Focus group testing demonstrated that “pre-

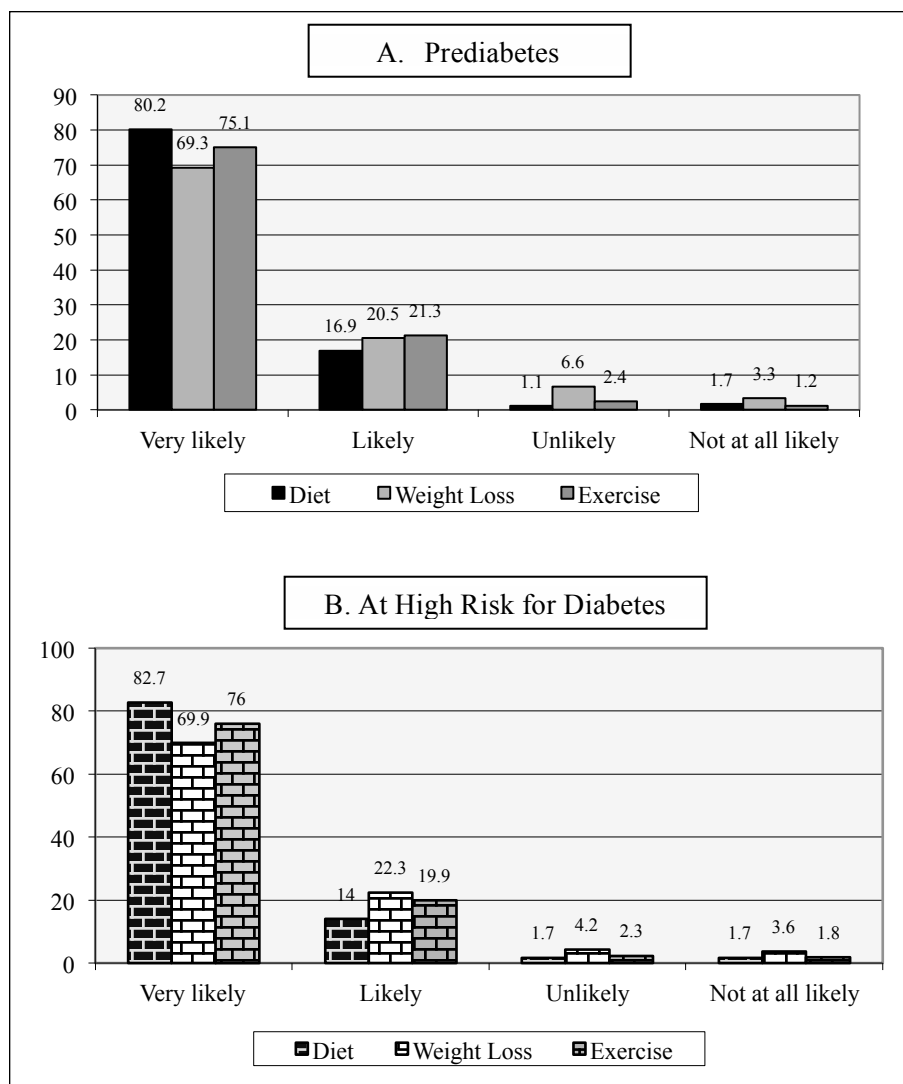


Figure 3. Comparison of intention to adopt lifestyle changes when the terms “prediabetes” (A) and “at high risk for diabetes” (B) were used. Patients responded in a similar manner when asked about their intention to adopt recommended lifestyle modifications, such as diet, weight loss, and exercise, regardless of the term used to describe their condition ($P = 1.00$, $P = 0.58$, and $P = 1.00$, respectively).

hypertension” was understood by patients and primary care practitioners before the seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure¹⁹ changed it from the prevailing corresponding descriptive terminology “high normal blood pressure” in 2003.^{19,23} To our knowledge, there has, until now, been no similar discussion in the literature

regarding patients’ understanding and the resultant effect of diabetes risk terminology.

The diabetes epidemic continues and, because of its huge economic impact, threatens the viability of most health care systems. Importantly, disease prevention in this case is both possible and cost-effective. However, we need to develop practical strategies to translate what we have learned from diabetes prevention clinical trials into

the real-world setting. Recognition of diabetes risk may be considered the motivational cornerstone for initiating lifestyle changes, such as healthy diet, exercise, and weight loss.^{10–12} Very clearly, to succeed in diabetes prevention, patients must be actively engaged in the process. The first step is effective communication about risk and how it may be mitigated.

A small but measurable proportion of our patients expressed difficulty in understanding the meaning of these terms—9.6% for “prediabetes” and 5.9% for “at high risk for diabetes”—at least in the context of our written survey, admittedly a somewhat artificial construct that comprised our study methodology. Consequently, we suggest confirming that the language used with patients is properly understood in live discussions.

Our study has several limitations. Assessment of patients’ comprehension by administration of a printed survey is not the same as informing patients in spoken word, which is the usual paradigm of medical practice today. A related limitation is that our study participants did not have an opportunity to clarify any questions they could have had while completing the survey. In real-life encounters with clinicians, patients may have a greater opportunity to clarify their understanding of these terms. We made the assumption that the education level among study participants was adequate to understand the questions, and no specific literacy evaluation was undertaken. We did, however, attempt to minimize the language barrier for Spanish-speaking patients by providing them with an option to complete the survey in Spanish (14.4% of respondents). This approach allowed us to evaluate this high-risk group of patients and

decrease bias stemming from misunderstanding the questions.

Another potential concern is the somewhat subjective nature of the data derived from surveys. Our patients' responses may reflect a high apparent motivation and intention to adopt required lifestyle changes. However, as is commonly encountered in practice, it may ultimately be difficult to translate these initial commitments into reality.

Our study design did not allow for randomization of patients to one or the other terminology. It is possible that asking a subject about two different terminologies meant to convey the same message may have diluted any potential differential interpretations. Such differences might be found, however, if two similar groups of individuals were randomly assigned to receive one or the other at-risk designation and were then compared. Such a design would necessarily involve more patients but should be considered as a follow-up study to confirm our findings.

We also did not preselect a high-risk group. We feel it is unlikely, however, that such a focus would have necessarily changed the outcomes of our study, particularly given that our population appeared to be generally a high-risk one. A related concern is that we essentially surveyed one socioeconomic stratum; it is therefore unknown whether our results could be extrapolated to a more general population. However, this single clinic cohort certainly represents a vulnerable group of individuals, based on their ethnicity, weight, and education level. Of note, the majority of the patients in this study had at least one diabetes risk factor, and most of them had more than one; therefore, the study subjects, although selected randomly, did indeed represent a high-risk group. Interestingly, only

34.5% of our study participants actually thought they were at risk for diabetes, based on the survey. This suggests that many patients are not aware of their risk factors—an important opportunity for more education from HCPs. Future studies in this area should be extended to different practice settings and different socioeconomic groups to determine whether our findings can be replicated therein.

There was an imbalance in the specific term sequence of the surveys, with 59% more patients completing the version that began with the “prediabetes” set of questions. The only significant order effect was observed in questions about understanding the terms. The reason for this finding is not clear. We feel that the inequity in the specific term sequence and positive order effect should not affect the general interpretation of our study because the overall responses were analogous for both terms and, generally, there was little interaction by sequence.

The results of our study revealed that patients similarly understand the two most commonly used diabetes risk descriptions. Both terms appear to have a similar and significant personal impact. Study subjects reported that they were equally highly motivated to implement diet, weight loss, and exercise when asked about recommended lifestyle interventions regardless of which term was used. We suggest that HCPs ensure that whatever terminology is used in this regard be well understood by patients. Of course, a patient's understanding of the terminology does not necessarily predict that patient's adherence to lifestyle advice to reduce risk. We therefore recommend tailoring interventions to individual patients to reduce their personal risk. More research is needed to further study

this important question, particularly randomized, controlled trials in which the actual effect of lifestyle changes can be quantified.

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